393 Transition to adulthood for young people with CF

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This PhD study is examining the lived experience of the transition to adulthood for a group of young people with CF. In so doing it aims to establish the young people's aspirations for adult life and to explore the impact of external factors on these aspirations and their transition to adulthood. This research has adopted the phenomenological approach, using the traditional data collection method of qualitative in-depth interviews.

In the first stage of this research in depth semi structured interviews were conducted with a group of young people with CF aged 16–17 years. Initial analysis has so far generated a variety of issues with regards to the transition to adulthood including: concerns regarding the move to adult care such as pain relief and many participants felt unprepared for the move to adult care; the importance of routinisation of their treatment regimes into their daily lives; a need for the consequences of non-adherence to treatment to be placed in the context of their daily lives; the importance of being treated normally and leading a normal life in spite of the condition; the misconceptions held by the general public with regards to the condition as a result of the bleak picture painted by the media and the potential barriers CF may present in them achieving their aspirations such as being able to living independently and holding down a job.

The results yielded so far have revealed much individual variation and as such it is necessary to widen the sample group. In the following stages of research a second interview will be conducted with each of the participants in approximately one year's time after they have transferred to adult services. This will extend insight into the ongoing process of transition to adulthood. In addition subjects who have already transferred from pediatric to adult care within the last 18 months will be interviewed.

394* Harmonization of transition to the adult CF centre in Paris area

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Until now, in the Paris area, nothing had been organized to manage transition from pediatric to adult CF centres. As part of a project on transition, we focused on the organization of an homogeneous process.

A two step study was performed. First, we interviewed pediatric and adult physicians and coordinating nurses on their practices and wishes. Newly transferred patients to the adult centre (and parents when possible), were asked about the change (positive and negative aspects, possible improvements). Caregiver practices appeared to be heterogeneous (when and how to approach and organize transition and its post-period, ...). Patients mostly evoked a "just in time" or a too late change of CF centre, and the lack of information on the new adult team. They also regretted not to be more involved in the process of transition.

Then, based on the analyses of interviews, we elaborated a "transition kit". It included a welcome letter, maps of the hospital and care centre, a "who's who" of the adult care team. The pediatric nurses were asked to fill out a sheet on the follow-up (social, demographic, nursing and personal data). Pediatricians received a list of documents required to begin the follow-up at the adult centre. Finally, we set up a questionnaire in order to evaluate the level of knowledge of the patient on the disease, that should be answered by the pediatric team and transmitted to the adult team.

Harmonization of transfer practices offers new opportunity to improve the quality of follow-up of CF patients in the Paris area and could be extended to other CF centers.

We thank Vaincre La Mucoviscidose for supporting the study and all caregivers that contributed to the study from Necker, Robert Debré, Trousseau and Versailles pediatric CF centres and Cochin and Foch adult CF centres.

395* Evaluation of a pilot Cystic Fibrosis "pre-graduation" clinic

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Our CF adolescent transition program starts at age 10 and culminates with "graduation" of the patient to the adult CF clinic at age 18. To strengthen this established program, we have developed and evaluated a one day pilot "pre-graduation" clinic/workshop 1 to 2 years before this transfer. The main objectives were to provide age-appropriate CF education to the six CF youth who were chosen to participate, as well as to provide more indepth information about the adult clinic and its care team than might be gleaned within the standard transition program. The day started with a regular CF clinic appointment, followed by a lunch and presentation by the adult CF clinic coordinator. In the afternoon, the youth participated in a workshop which included a "Medication Jeopardy" game designed by the CF pharmacist; "Saying Goodbye" exercises by the youth child life specialist; "Sex Talks" by the youth clinical nurse specialist; and an informal talk with a CF clinic 'graduate' now attending the adult clinic. A "pre/post" questionnaire about the transition process, the adult CF clinic, and basic CF pathophysiology was administered to all youth participants before and immediately after the afternoon workshop. Only 2/10 questions were answered correctly by all 6 patients before the workshop, while all 6 patients correctly answered 7/10 questions afterwards, and 5 correctly answered 8/10. All youth agreed that the day was useful and enjoyable, and written comments indicated that they felt more knowledgeable about the expectations of adult caregivers.

Results of feedback and pre/post questionnaires indicate that a Pre-Graduation clinic is an effective component of a comprehensive CF adolescent transition program.

396 Consultation on transitional care needs of young people with cystic fibrosis (CF)

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Background: We have observed that transition from the paediatric to adult service can be a distressing experience for the young person and their parents and lack of consistency can occur when coordinating transfer. An audit was performed as a starting point for transitional care implementation.

Aim: To obtain the views of 11–16 year olds on transitional care a long with the views of their parents/carers. To evaluate previous experiences of adults with cystic fibrosis on their transition experience and views on transitional care. To develop a designated transitional care package for young people and families with cystic fibrosis based on this audit.

Method: Adapted questionnaire already used in the CF arena regarding development of transitional care. 13 pre-transitional children (11–16 years) and their parents/carers and 12 adults (17–25 years) were recruited. Guided questionnaire completion was conducted by both adult and paediatric cystic fibrosis specialist nurses during routine clinic visits.

Results: 77% children, 40% parents/carers, 75% of adults felt that planning transition should occur between the ages of 14–16 years. 92% of children, 90% parents/carers, 83% of adults felt that the transition process should take between six months and two years to complete. 100% of parents/carers and adults, 92% of children felt that both adult and paediatric CF teams needed to participate in the transition process

Conclusion: This audit has enabled a change in practice and promoted the smooth transition of children with CF to adult services. We actively involved the child/family in the development of a transitional care package. This is the first time adult views on transitional care have been used to shape a transitional care program.